Sadinsky and Associates
405 Lisgar Street, Suite 100, Ottawa, Ontario K1R 5G9

For Discussion Purposes Only

A WORKING DOCUMENT
For The
Development Of A National Strategy
On
HIV Infection And AIDS

This document has been prepared by the firm of Sadinsky and Associates.

The findings and positions contained herein are those of its principal investigators, Ian Sadinsky and Dr. Earl Berger.

October 1989

Communications Planning
Management Strategy
Policy Development
Programme Evaluation
Government/Industry Relations

90-05946/

Sadinsky and Associates
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Ms. Margaret Catley-Carlson
Deputy Minister
Health and Welfare Canada
Jeanne Mance Building, 21st Floor
Tunney's Pasture
Ottawa, Ontario
K1A 0K9

Dear Ms. Catley-Carlson:

We are pleased to submit a final copy of "A Working Document for the Development of a National Strategy on HIV Infection and AIDS".

We believe this Working Document could form the basis for consultations with the provinces, community-based organizations, and other interested parties. Therefore, it is imperative that those receiving this document realize that this is not the final National AIDS Strategy itself, but rather a process document designed to facilitate the development of the National Strategy.

The findings and positions put forward in the Working Document are those of myself and my colleague, Dr. Earl Berger, and we take full responsibility for all errors of commission or omission.

The Working Document is designed to generate consultation with a view to producing a National Strategy before the end of the calendar year.

We look forward to receiving comments and direction from you and other parties receiving the Working Document as soon as possible so that we can carry out the next steps in developing the National AIDS Strategy.

Sincerely,

Ian R. Sadinsky
President

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THE DEVELOPMENT OF A NATIONAL STRATEGY ON HIV INFECTION AND AIDS

1.0 INTRODUCTION

1.1 The Need for a National AIDS Strategy

The Human Immuno-Deficiency Virus (HIV) is the causal agent of Acquired Immuno-Deficiency Syndrome (AIDS). No one can develop AIDS without first contracting HIV.

HIV is contagious. The confirmed routes of transmission are:

- anal intercourse, inadequately protected, with an infected person;
- vaginal intercourse, inadequately protected, with an infected person;
- the transfusion of contaminated blood, blood products, or the transplantation of contaminated organs or tissues from an infected person;
- the use of needles contaminated by an infected person;
- from an infected mother to her unborn infant.

HIV is not transmitted through casual contact, food, insects or toilet seats. Unfortunately, the infection is exceptionally difficult to treat: the virus integrates into the infected cell's genes; and the cell cannot be cured of the virus without being killed itself. Currently available therapies, such as A.Z.T. and D.D.I., can only slow down the virus' growth. The individual remains contagious and will eventually develop AIDS.

Estimates of the number of HIV-infected Canadians range, depending upon the assumptions used, from about 30,000 to more than 100,000. By October 30, 1989, 3,125 Canadians had been reported to the public health authorities as having AIDS. The actual number of AIDS cases is almost certainly higher than the reported number of cases. Of the reported cases, 1,837, or 59 percent have died. Of the cases reported between 1982 and 1986, about 85 percent have died.

There is widespread agreement on the need for a National AIDS Strategy because of the disease's unique and dangerous combination of characteristics: the very intimate modes of HIV transmission; the long period of asymptomatic HIV infection; the devastating and usually fatal nature of AIDS; the openings HIV infection creates for opportunistic diseases which themselves are often fatal; AIDS' impact on individuals, families, friends, communities, and on government health, social and other services; and the fact that no vaccine or cure yet exists for HIV infection itself or for some of the attendant opportunistic diseases.

Given these characteristics of HIV infection and AIDS, a National Strategy on AIDS is essential. A National Strategy would establish national objectives and strategic actions to encourage and mobilize the participation of all sectors to deal with all aspects of the effort against HIV infection and AIDS. This would include action, both individually and in partnership, of all levels of government, non-governmental organizations, community-based groups, persons with AIDS (PWAs) and other groups and individuals working in the area of HIV infection and AIDS.

A National Strategy would maximize coordination, minimize duplication and overlapping and encourage the optimum effectiveness of available resources. A National AIDS Strategy would establish the framework for identifying, developing, coordinating, monitoring, and evaluating policies and programs on a national basis to ensure maximum effectiveness in addressing national issues related to HIV infection and AIDS.

1.2 The Purpose of the Working Document

The purpose of this Working Document is to provide a basis for consultation leading to agreement and commitment to the basic objectives of a National AIDS Strategy, and to establish the points of agreement and disagreement on specific policies and programs.

This Working Document seeks to elicit responses to a set of proposed strategic actions, and to the proposed allocation of primary and corollary responsibilities for the individual policies and programs.

1.3 Methodology for Developing the Working Document

The information contained in this document results from the extensive consultations of Sadinsky and Associates, and its two principal investigators, Ian Sadinsky and Dr. Earl Berger, during the period of June 1, 1989 to October 20, 1989.

The Consultants met separately with: the health departments of each province and territory and representatives of some provincial education departments; the Canadian AIDS Society and a number of its local member groups, including PWA groups, across the country; the Canadian Public Health Association; the Canadian Hemophilia Society; the Canadian Medical Association; the Canadian Life and Health Insurance Association; Native organizations, researchers, primary care providers, hospitals, clinics, and hospices, and others.

In addition, the Consultants met with the Minister of National Health and Welfare, the Deputy Minister of National Health and Welfare, the National Advisory Committee on AIDS (NAC-AIDS), and numerous organizations within the department directly or indirectly involved with AIDS including: the Federal Centre for AIDS; Health Services and Promotion Branch; Policy, Communication and Information Branch; Medical Services Branch; Health Protection Branch; and the Canadian Blood Committee. Representatives of international health organizations and of other countries were also consulted.

The Consultants undertook a review of the available literature on national, regional, and local AIDS strategies, as well as the bio-medical and psycho-social characteristics of HIV infection and AIDS; current and proposed methods for prevention, control, treatment, care and support; estimates of the cost impacts of the infection; the international dimensions of HIV infection and AIDS; and legal and regulatory aspects of HIV infection and AIDS.

Two organizations, the Canadian AIDS Society and the Vancouver Persons with AIDS Society, submitted briefs to the Consultants; other organizations submitted materials on various subjects.

The Consultants acknowledge that their consultations were limited due to constraints of time and availability. They believe, however, that the majority of major principles and issues were addressed during the first round of consultations, and that omissions can be captured during subsequent consultations.

1.4 Criteria for Developing a National Strategy

The Consultants used the following criteria in their discussions across the country and in developing this Working Document for the development of a National Strategy:

* The National Strategy will be developed through a broadly-based process of consultation among the federal, provincial and territorial governments, non-governmental organizations, health and care-givers, community groups, persons with AIDS and other interested groups and individuals.

* Whenever possible existing mechanisms and organizations will be utilized for the consultative process in order to expedite the process and the implementation of the National Strategy.

* Regional interests and diversity will be recognized.

* The social and cultural diversity, and the human rights of the ill and those at-risk, will be respected.

* The National Strategy will promote the coordination of resources to achieve maximum cost effectiveness.

* The Strategy will be responsive to the changing state of the art in the biomedical and behavioural sciences.

* The benefits of international experience will be maximized.

1.5 The Urgent Need for a National AIDS Strategy

The circumstances of HIV infection and AIDS in Canada justify immediate, urgent action. The experience in other Western countries is that the infection can spread with blinding rapidity, affecting all regions, classes and groups in society, swamping human and physical resources.

It is imperative, therefore, that the federal government, and its departments and agencies, and the provincial and territorial governments, and their departments and agencies, along with the national and community organizations, increase the tempo of their individual and collaborative efforts. There is an urgent need for agreement on what is to be done, who is to do it and the mechanisms through which it will be done.

This document summarizes the current situation and sets out proposals for on-going and new actions. It provides a common basis to which all concerned can respond immediately, so that the second stage of

consultations can begin without delay. It may not be possible for each party to respond to each issue and proposal in this Working Document with equal attention or detail within a short period of time. Some issues will take longer to think through and to reach agreement on. It is possible and imperative, however, to work immediately on what can be discussed and agreed to, and to set in place mechanisms for resolving the more difficult issues in a timely way.

2.0 THE NATIONAL AIDS STRATEGY

2.1 Draft Objectives

The first stage of consultations and the review of the literature generated a series of recurrent ideas, principles and themes. From these, the Consultants developed five objectives which they propose as the framework for the long-term requirements of the National AIDS Strategy.

The five proposed objectives are:

I. Establish the dimensions and characteristics of HIV infection and AIDS in Canada.

II. Break the chain of transmission of infection through cooperative, targetted behaviour change programs.

III. Contribute to the effort to develop a vaccine for the HIV infection and effective therapies for AIDS and its related diseases.

IV. Ensure that those who are infected and their supporters and care-givers have access to appropriate treatment, care and support services.

V. Strengthen national mechanisms and partnerships to facilitate national cooperation and collaboration to optimize the use of available resources.

Objective I establishes the need to determine the incidence of AIDS and the seroprevalence of HIV infection in order to establish appropriate surveillance, prevention and control mechanisms. It also establishes the need to go beyond the bio-medical aspects of HIV infection and AIDS to

examine the broader social, economic, moral, legal, and other dimensions of HIV/AIDS.

Objective II requires a set of strategic interventions to break the chain of transmission of HIV infection by addressing and eventually eliminating high risk behaviour. Only in this way can the burdens of treatment, care and support, borne largely by the provinces and by the ill, be eased.

Objective III recognizes Canada's role in research nationally and internationally to develop a vaccine for HIV infection as well as therapies to control and cure AIDS and its related diseases.

Objective IV recognizes the life situation of persons with HIV infection and AIDS and establishes the need for state-of-the-art, equitable, and accessible treatments, care, and support services for these persons, their families, supporters, and caregivers. It also recognizes the need to ensure that the human rights and dignity of those infected and ill are respected as part of their rights as Canadians.

Objective V defines the commitment to a National AIDS Strategy through the establishment of a national mechanism to manage Canada's response to the disease: to provide direction and advice; to initiate, coordinate and evaluate policies and programs on a national basis; to assist in inter-regional activities; and to avoid duplication and overlapping, and thereby facilitate the most efficient and effective use of financial and human resources in the implementation of the National AIDS Strategy.

2.2 Strategic Principles - Leadership, Partnership and Commitment

To achieve these national objectives, several strategic principles are essential. The three components - leadership, partnership and commitment - are key to the success of the National AIDS Strategy.

1. **Leadership** - Leadership of the national effort is the responsibility of the federal government, and specifically, of the Minister of National Health and Welfare. The Working Document suggests the formation of a new body for the management of the Strategy (see Chapter 7). It is assumed that the Department of National Health and Welfare would exercise its leadership through that forum and through the fulfillment of its established responsibilities.

   Concomitantly, it is assumed that political leadership will be exercised vigorously at the other levels of government and among the other partners to the National Strategy.

2. **Partnership** - The National Strategy would represent an agreement amongst all participants that they are engaged in a partnership with each other to achieve the objectives of the Strategy. Partners would include the federal government, the provincial and territorial governments, national, regional, community and other non-governmental organizations, organizations of PWAs, the private sector, and other bodies specifically mentioned in the final version of the National Strategy.

   The National Strategy would promote the partnership of these organizations at the appropriate level of participation in the implementation of specific activities under each objective so as to maximize the contribution of each to the overall effort.

3. **Commitment** - HIV infection and AIDS are long-term phenomena. New therapies and the possibility of a vaccine and cure offer the possibility that in the not-to-distant future, HIV infection will be transformed into a curable or at least a more conventional chronic condition. In this best of scenarios, the National Strategy could be regularized, and its component parts absorbed into the partners' mainstream activities of treatment, care, support and prevention.

Until that time, the National Strategy would require a vigorous and unflagging commitment from its partners to the fulfillment of its objectives.

2.3 Proposed Structure and Responsibilities

The Working Document contains a discussion of the rationale for each proposed strategic objective. This is followed by a chart which proposes specific activities for that objective; and the partner or partners who would assume primary responsibility for that activity, and the partner(s) with corollary responsibilities.

Strategic Activities

* The proposed strategic activities for each objective follow from the rationale for that objective, and are intended to produce specific results directly pertinent to the achievement of that objective. The list of activities is a first estimate of what needs to be done. The activities would be under continuing review and would be revised as circumstances dictate.

Monitoring and Evaluation

* The National Strategy would call for the implementation of a wide range of strategic activities. Built into each activity should be a component for monitoring and evaluation. Effectiveness would be evaluated and revisions made to each program activity as appropriate by the responsible partners.

Primary and Corollary Responsibilities

* The Working Document proposes that for each activity, a partner or partners, accept primary responsibility for the implementation of that activity and its successful completion. The allocation of responsibility in each case is based upon existing established areas of responsibility or organizational suitability.

* The bulk of the primary responsibilities for implementing the activities within each objective fall within the purview of one of the two senior levels of government.
* It is expected that, in turn, each province and territory would allocate those responsibilities within its purview among its departments, municipal governments and other agencies as it deems most efficient and effective.
* Where the division of responsibility is unclear or overlaps - for example, in the area of research - the Working Document proposes that primary responsibility be allocated to that partner deemed most experienced or best suited to carry it out, with corollary responsibility allocated to the other partners as appropriate. The underlying principle is to reduce overlapping and to maximize the benefits of available resources.
* Our findings indicate that particularly with respect to health promotion and behaviour change programs, the most effective results are often generated by regional, community, and other organizations close to the targetted groups and individuals.
* The Working Document recommends that the partnership of the private sector, including unions, employer organizations and individual companies be promoted. This would include collaboration in implementing specific activities, providing advice, and financial support.
* The Working Document supports the principle of joint funding of various activities. The intent is to share responsibility among the partners as appropriate, and to demonstrate commitment to the fulfillment of the objectives. The allocation of funding responsibilities is the responsibility of the partners.

3.0 THE DIMENSIONS OF HIV INFECTION AND AIDS IN CANADA

Strategic Objective I:
Establish the Dimensions and Characteristics of HIV Infection and AIDS

RATIONALE

An essential part of the National AIDS Strategy would be the determination of the extent of HIV infection in Canada. Information on current infection rates is vital for long-range planning and resource allocation, and to target prevention efforts most effectively.

3.1 Seroprevalence Studies

The first priority would be to determine current HIV infection rates in defined population subgroups through various studies such as of patients at sexually transmitted disease clinics, of childbearing women, and from specimens from routine diagnostic laboratory procedures. These studies would be undertaken using the anonymous, unlinked methodology in order to maximize the accuracy of HIV seroprevalence estimates. This approach utilizes blood left over from routine diagnostic procedures; blood specimens are completely unlinked from any personal identifying information in order to ensure anonymity.

It would be appropriate for the federal government to continue to have responsibility for the coordination and funding of national HIV seroprevalence studies in order to ensure a standard approach to their conduct and interpretation. Priorities for these studies would vary geographically, and consultation with provincial governments and AIDS

researchers would be necessary to develop a comprehensive research plan.

The ethical issues involved in the conduct of seroprevalence studies have been addressed by a working group of legal and ethical experts from across the country. The deliberations of this group resulted in the production of guidelines for the ethical conduct of HIV seroprevalence studies. These guidelines should constitute the essential criteria for this research in Canada.

In view of the importance of these data, it is considered essential that NHW provide increased direction and coordination in this area.

3.2 Seroepidemiologic Studies

Seroepidemiologic studies designed to determine the prevalence of HIV infection, and the risk factors associated with infection in defined groups, are required to characterize target populations, and to determine the risk behaviours and their relationship to infection rates. In contrast to the anonymous, unlinked methodology described in 3.1, this type of research is undertaken with the informed consent of individuals and includes collection of risk factors and demographic information.

Target populations for these studies include homosexual men, bisexual men, injection drug users, and persons with high rates of sexually transmitted diseases.

Both the federal and provincial governments have a role in supporting the conduct of seroepidemiologic studies. The federal government's priority should be on collaborative, multi-centre studies which represent large geographic areas.

3.3 Surveillance and Reporting

3.3.1 AIDS

The National AIDS Case Surveillance Program was instituted in 1982 with the objective of describing the epidemiology of AIDS in Canada and monitoring changes over time. AIDS is a reportable condition in all provinces and territories. The usefulness of this Program depends upon the accurate and complete reporting of AIDS cases by physicians. As with any surveillance program, it is recognized that under-reporting does occur. A collaborative study by the Federal Centre for AIDS, and researchers from the University of British Columbia and the University of Toronto quantified the rate of under-reporting to be 15%. This is comparable to rates reported from the U.K. and the U.S. Monitoring under-reporting rates should continue in order to adjust current statistics and to improve the accuracy of future projections.

The coordination of the National AIDS Case Surveillance Program is the responsibility of the federal government. Consultation with provincial governments is necessary to maintain standardized reporting mechanisms.

3.3.2 HIV Infection

Positive HIV antibody test results are reported, either nominally or non-nominally, in all provinces and territories. Reporting is legally mandated in all provinces and territories, with the exception of British Columbia, Alberta and Quebec.

In order to maximize the usefulness of available data from diagnostic testing for HIV infection, the National Strategy should encourage standardization of reporting practices nationally.

3.4 Reference Services

Due to the nature of the virus, the large number of sera which test as HIV antibody indeterminate by immunoblot will continue to demand the services of a national reference service.

Reference services for ELISA and confirmatory testing are also required together with proficiency testing and quality control at the national level. Diagnostic kits and commercially produced reagents and medical devices and blood products need to be evaluated by a national reference service.

There is a need to maintain the national reference capability with respect to the laboratory services of the National Retrovirus Reference Centre of the Department of National Health and Welfare. Reference services also include international activities (for example, as a World Health Organization Collaborating Centre).

In order to be able to provide effective and up-to-date diagnostic reference services, some limited methodological research must be undertaken: examples of this include the development of new antibody test methods, the ability to culture viruses, and the implementation of diagnostic tests such as the polymerase chain reaction test. This is discussed in greater detail in Chapter 5 (see 5.1).

3.5 Economic Analysis

Incomplete as the current seroprevalence data are, they should be used to begin developing economic analyses of the effects of the infection. The economic analysis model(s) should include both direct and indirect costs.

Direct costs include such activities as testing, treatment, care and support.

Indirect costs include such components as bio-medical and psycho-social research, loss of productivity, and costs of public administration.

The economic analysis model(s) should be revised and updated as the seroprevalence and cost data improve. The economic analyses need to be related to HIV infection within each province and territory so that each can more efficiently deploy its funding and human resources. The analyses should also incorporate the relationship between expenditures on such activities as biomedical research and prevention and the subsequent long-term savings in treatment, care and support.

3.6 Human Rights Issues

Human rights issues cut across all dimensions of the HIV epidemic. In any epidemic, infected individuals face discrimination. With HIV infection and AIDS, the situation is aggravated because, at this time in Canada, eight in ten HIV-infected individuals and PWAs are male homosexuals, a group traditionally facing overt and covert discrimination. Discrimination on the basis of sexual orientation is not protected against under the Canadian Human Rights Act. Protection of individual human rights under provincial/territorial legislation on the basis of sexual orientation exists in only four jurisdictions.

Another large and expanding infected group, - about four in 100 infected - are injection drug users, another marginalized population. Legislation under the Criminal Code of Canada, coupled with increased public awareness and involvement in the "war against drugs", are factors that directly influence and impact on public health and health promotion measures designed to reduce the spread of HIV amongst injection drug

users. Closer collaboration among the health, social, legal and law enforcement sectors needs to be developed and maintained.

Anecdotal evidence suggests many individuals engaging in high risk activities have or will refuse to participate in voluntary testing as well as in seroprevalence surveys and contact tracing unless their human and legal rights are protected.

Many individuals at risk fear that exposure of their private behaviours will result in loss of employment and housing, isolation from family and friends and the loss of other necessities of day-to-day life. These fears are aggravated by those instances where public exposure has resulted from breaches of rules of patient-physician confidentiality. Legislation and regulations in all jurisdictions must protect the rights of individuals to confidentiality regarding HIV test results and HIV status.

Issues pertaining to private and public rights and obligations regarding HIV infection must be resolved in a consistent manner in all jurisdictions. Human rights legislation in all jurisdictions should prohibit discrimination on the grounds of HIV infection and presumed HIV infection.

AIDS organizations have consistently argued that human rights legislation in all jurisdictions should also prohibit discrimination on the grounds of sexual orientation. This issue is part of a larger, long-standing debate in Canadian society. Solely from the perspective of a National Strategy on AIDS, or indeed of any public health effort pertaining to AIDS, the effects of discrimination on the grounds of sexual orientation upon that effort appear to be substantial. Clearly, this issue needs to be addressed as part of the National AIDS Strategy. From the perspective of a healthy Canada, failure to resolve this issue fairly may be very costly.

Social reform does not necessarily follow legal reform measures designed to protect the rights and entitlement of people with AIDS and HIV infection. The health and economic status of persons directly affected by discriminatory acts are often barriers to advancing their cases through the courts. Bold leadership, and the development of effective strategies and approaches to reduce public fears of disease and sexuality, are essential components for eliminating discrimination, and improving the opportunities for prevention and effective treatment.

Strategic Plan/Objective I:
National Dimension

	Strategic Activities	Primary Responsibility	Corollary Responsibility
I-1	Expand the national seroprevalence study program	NHW	- Provinces - Universities - Medical profession
I-2	Continue to support seroepidemiologic studies	NHW	- Provinces
I-3	Maintain and improve national surveillance systems	NHW	- Provinces - Medical profession
I-4	Maintain national bio-medical reference services	NHW	- Provinces - Medical profession
I-5	Survey the numbers and characteristics of family, friends, and care-givers of persons with HIV infection and AIDS	NHW	- Provinces - Community groups
I-6	Develop an independent model of the direct and indirect costs of AIDS	Economic Council of Canada	- NHW - Provinces - Community groups
I-7	Develop a national accounting of financial and human resources dedicated to HIV infection/AIDS	NHW	- Provinces - Community groups
I-8	Develop a study of the non-medical, non-financial aspects of AIDS	CHRC	- NHW - Provinces
I-9	Revise federal and provincial human rights legislation	- Federal - Provincial	-

4.0 BREAKING THE CHAIN OF TRANSMISSION

Strategic Objective II:
Break the Chain of Transmission of Infection Through Cooperative, Targetted Behaviour Change Programs

RATIONALE

HIV infection is preventable. The National Strategy should propose a fixed time frame, such as five years, to achieve a substantial and defined reduction in the transmission of HIV infection. A date for zero growth in the rate of transmission of the infection should be determined once the seroprevalence data are available. Given the inadequacies of available therapies, breaking the chain of transmission is the only way to stop the increasing personal, private and public costs of the illness, treatment, care and support.

4.1 Prevention and Education Strategies

Traditionally, prevention programs have been based on a formulation of the "host-agent-environment" model. This approach has been successful in many instances: e.g. the control of malaria. However, prevention programs related to sexually transmitted diseases have been relatively ineffective, as witnessed by the spread of gonorrhea and chlamydial infection in the general population. If HIV infection were to spread to a comparable degree, the results would be catastrophic.

Historically, individuals have been exceptionally resistant to government attempts to intervene in their sexual behaviour. Persons using addictive drugs have been similarly resistant to changing their behaviour. The challenge of the National Strategy is to achieve substantial success in a short period of time in areas of apparently intractable human behaviour.

To do so, the National Strategy must set in place programs which successfully encourage people to ensure that they do not infect others or allow themselves to become infected. To this end, public attitudes and public behaviour must be developed to support responsible, private behaviour.

4.2 Attitudinal and Behavioural Research

The Canadian population is diverse geographically, ethnically, culturally and socially. Successful behaviour change programs will need to address these diversities.

The research upon which behaviour change, prevention and education programs can be based is not abundant. Health and education authorities at all levels of government report that there is still not a great deal of information on sexuality and sexual values of Canadians in general, and of the place of sexual values and practices within the fabric of morality, behaviour, friendship and social interactions. The recent baseline research funded by Health and Welfare Canada - among youth and adults - needs to be continued and expanded.

Reducing the spread of HIV infection among injection drug users and their sexual partners is an immediate and urgent priority in the control of the transmission of this infection. There are long-standing federal and provincial research programs related to substance abuse, as well as the newly-formed Canadian Council on Substance Abuse. The National Strategy needs to address and build upon the findings and work of these agencies.

Within the National Strategy there should be provision for: (1) centralized collaboration and coordination among the three levels of government, researchers and community representatives, in the develop-

ment of research, sharing of research findings, discussion of common and particular themes, values and content: and (2) decentralized use of this research to develop specific messages for specified groups or individuals involved in particular high risk behaviours.

4.3 Targetting

With respect to HIV infection, some of the most successful behaviour change programs have been carried out by gay and hemophiliac organizations amongst their members, friends and the affected communities.

These behaviour change programs used various combinations of the media (posters, newspapers), group settings, social activities, counselling and other activities designed to: (1) encourage responsible behaviour; and (2) generate group attitudes and actions to support individuals seeking to behave responsibly.

The actual messages delivered in these programs reflect the language, values and practices of the individuals to which they were directed. In general, experience indicates that targetted messages reflecting community language, values and practices, and delivered by peers or those close to the target audiences, are the most likely to be convincing and to encourage the desired behaviour changes. This suggests that behaviour change programs regarding HIV infection are most likely to be effective when they involve the cooperation of those already infected or close to those infected.

Behaviour change programs need to incorporate such dimensions as:

- multi-level approaches (e.g. combined federal/provincial initiatives with community programs);

- o multi-dimensional interventions (e.g. awareness, knowledge, attitude change, behaviour change, peer support);

- o high frequency settings (e.g. school, workplace, media);

These programs must be closely monitored and evaluated to ensure cost-effective use of program resources.

4.3.1 Women

Women are at risk because, traditionally, the woman has been expected to be responsible for birth control and safer sex practices, and to accept the consequences of her partner's actions. The sexism imbedded in social custom, advertising and other public messages reinforces these traditional positions. Often, in this subordinate role, women are unaware of their partners' actions outside the relationship and unable to protect themselves adequately.

Promotion of the sexual equality of women is a necessary adjunct to breaking the chain. Equally, it is imperative that men of all ages learn to accept responsibility for their behaviour. The result would be not only a reduction in HIV infection, but also in other infections.

4.3.2 People in Isolated Communities

People living in isolated communities report high levels of sexually transmitted disease. Persons living in these communities are, therefore, likely at risk for HIV infection. The issue is being addressed, with respect to Natives, through the Joint National Committee on Aboriginal AIDS Education and Prevention. The National Strategy should provide a complementary and broader approach including federal and provincial/-territorial authorities, local organizations and companies operating in isolated areas.

4.3.3 Prisoners

Prisoners make up another type of isolated community. Prisoners appear to have significant rates of homosexual activity, therefore, and there appear to be many instances of injection needle use, including tatooing. To date, there has been little agreement on appropriate and effective measures to reduce the spread of HIV infection in prisons. The National Strategy needs to incorporate an on-going coordinating/advocacy role to deal with this issue in federal and provincial institutions.

4.3.4 Injection Needle Users

Injection needle users are a particularly difficult group to reach. The nature of their activities does not encourage easy targetting and the involvement of law enforcement agencies makes the situation even more difficult.

Injection drug use, the most common form of injection needle use, occurs in all classes and corners of Canada. There is evidence that it is most common among prisoners, street people, school dropouts and other economically marginal groups. But, it is also not uncommon among professionals and the wealthy. There is evidence in the United States of middle and upper income men and women indulging in casual, week-end injection drug use and infecting their spouses. There is no evidence that the same pattern does not exist in Canada.

4.3.5 Youth and Children

The Canada Youth and AIDS study offers persuasive evidence that substantial numbers of young people are engaging in sexual activities which place them at risk.

Education, especially education within the schools, is one of the single most effective tools in the long-term effort to end the transmission of the infection. But, one of the single most controversial aspects of HIV prevention is the school-based program. Of the several thousand municipalities and school boards across the country, relatively few have undertaken vigorous, on-going programs related to HIV infection. This omission is consistent with the reluctance of many local officials to deal effectively with the teaching of sexuality and underlying moral and social values.

4.3.6 Other Target Populations

Other groups which the National Strategy needs to review for targetting include:

- **Homosexual Men**

  Homosexual men have had outstanding success in reducing the rate of increase in HIV infection among themselves. There is, however, anecdotal evidence of an increase of the rate of transmission among young gay men, and of the resumption of unsafe practices among some older gay men.

- **Bisexual Men**

  Little is known about the number, behaviour and attitudes of bisexual men. Limited prevention programs directed to this population do not appear to have been effective. Much more research is required to develop effective prevention and education programs.

- **Sex Trade Workers**

  The safe sex practices of this group are highly variable and there is great potential for extended transmission of the infection.

- **Street People**

  Preliminary evidence suggests that persons in this group, already highly vulnerable in many areas, are equally vulnerable to transmission of HIV infection.

- **Hemophiliacs**

  Persons with hemophilia have a very low chance of contracting the infection now that the safety of the blood supply has been secured. The issue now is to continue supporting safe sex behaviour, monitoring results and providing other support services.

- **Ethnic Populations**

  There is ample evidence that various ethnic groups have different values and attitudes towards sexuality and sexual practices. Figures indicate that HIV infection is not confined to any one particular ethnic group. Provision must be made through the National Strategy to develop appropriate communications mechanisms and programs to reach these populations.

- **Physically Challenged Individuals**

  Persons who are significantly sight, hearing, and mentally disabled are often isolated from conventional media. Appropriate means must be developed to reach these populations.

4.4 National Programs

The emphasis recommended for the National Strategy upon targetted programs does not preclude nation-wide programs. The experience of social marketing experts suggests that nation-wide programs (i.e. a message or series of messages delivered across the country) are valuable in increasing and expanding awareness, providing moral suasion, enhancing knowledge and, to a limited extent, changing attitudes. However, the major work of attitude and behaviour change seems to occur much closer to the individual's personal sphere. Consequently, the purposes of nation-wide programs need to be specified in relation to targetted programs to ensure coherence, congruity, complementarity and mutual reinforcement.

Media play a major role in reflecting, reinforcing, and in altering, public values. Much of current programming, particularly commercial programming, "lifestyle" beer commercials and music videos, reinforce existing sexual behaviour. A major component of the National Strategy should be to work with and encourage programmers, performers, and advertisers to incorporate AIDS prevention values and messages in their products.

4.5 Testing

Early testing creates important benefits for the individual in the form of early intervention, early treatment, the likelihood of a longer life and the possibility of a cure. Consequently, from the perspective of the individual, early testing can be critically important.

Widespread testing for seropositivity is also an essential step in breaking the chain of transmission between the infected and the uninfected. Current procedures for confidential testing are not always perceived to be effective in preserving the individual's right to privacy. There is

considerable anecdotal evidence that persons who think they may be seropositive are reluctant to present themselves for testing because of fears that confidentiality will be breached.

The National Strategy should call for voluntary testing through easily accessible clinics across the country. Testing should be accompanied by pre- and post-test counselling. In keeping with the need to encourage testing and to maintain confidentiality, reporting laws regarding seropositivity and AIDS should be reviewed where required regarding non-nominal testing.

To reinforce the importance of confidentiality and of the rights of individuals, the National Strategy should call for the provinces to enact legislation imposing liability for breaches of confidentiality without proof of damage, except in certain cases noted below.

Where seropositivity is confirmed, partner notification and contact tracing should be the responsibility of the infected individual and should be undertaken immediately following receipt of the test results and counselling. The state, however, has a vital interest in protecting public health, and therefore in ensuring that partners and contacts are informed of their risk as soon as possible. In cases where the health-care provider has reason to believe that the infected person has not notified partners and known contacts immediately, the National Strategy should provide for the doctor, public health authority or other appropriate professional to make such notification without the consent of the infected individual.

Mandatory testing should be required in cases involving donated blood, blood products, donated organs and tissues.

The National Strategy will need to resolve the issues concerning the testing of immigrants, hospital patients and staff, and of other groups who may be deemed to place others at risk.

4.6 Workplace Programs

There are three types of programs in the workplace which should be addressed in the National Strategy.

Infection. There are rare cases of accidental transmission in workplace settings. Nonetheless, there is evidence of widespread concern among various service sectors - police, firefighters, hospital workers, corrections staff - that they are at risk. Appropriate guidelines, training and information and other programs are needed for workplace sites outside health-related facilities. Public institutions, and the governments to which they are responsible, should ensure these programs are put in place.

Employee Support. Workers coming into contact with HIV-infected colleagues in the course of their daily activities need to be informed about modes of transmission and of the improbability that they can become infected. Employers have the responsibility to put the necessary programs in place. There is already some activity in this area across the country. The National Strategy should call for these activities to be encouraged and expanded, and for the employers to build on each other's experience.

Conversely, infected employees often need counselling which can be provided through employee assistance programs.

Prevention. There also is an opportunity at the workplace for educating and teaching prevention. The effectiveness of such programs should be evaluated both as "stand alone" programs and as part of larger local, regional, and national programs.

4.7 Leadership

The nation-wide consultations leading to the development of this Working Document found numerous examples where political leadership was wanting, where public health and education officials were hamstrung by their cabinet, council or board.

There is somehow in the Canadian psyche the conviction that it is better to risk a child's life, than to talk to that child about penises, vaginas and condoms. The World Health Organization in 1975 referred to the "right to sexual information". The right to information, and the accompanying education in values and ethics, has taken on a life-and-death dimension with HIV infection and AIDS.

Success in breaking the chain of transmission depends on the implementation of sustained, vigorous and aggressive interventions aimed at behaviour change. The National Strategy will require determined, unflagging political leadership at all levels and in all sectors.

Efforts to help people protect themselves against a potentially fatal disease are inherently moral; failure to help people protect themselves is inherently immoral.

Strategic Plan/Objective II:
Breaking the Chain of Transmission

	Activity	Primary Responsibility	Corollary Responsibility
II-1	Undertake national studies on sexual values and practices and behaviour change phenomena within the general Canadian population and directed towards specific groups (Natives, ethnic populations, injection drug users, homosexuals, bisexuals, street people, sex trade workers, prisoners and persons living in isolated communities)	NHW	- Provinces - Community groups
II-2	Provide national reference services for baseline social and behavioural research on sexual values and practices, IV drug use, and other high risk behaviour	NHW	
II-3	Develop and implement a national information and awareness campaign geared to community-based and individual counselling, education and prevention (to include a major component for youth and women)	NHW	- Provinces - Community groups
II-4	Develop and implement targetted behaviour change and education/prevention programs, including evaluation of effectiveness for specific groups in II-1	Provinces Federal	- Municipalities - Community groups - Private Sector - Educational Institutions
II-5	Provide a Comprehensive Clearinghouse/ Information Service of AIDS-Related Education Materials	NHW	- Federal - Provincial - Community groups - Universities
II-6	Encourage the development of non-medical barriers to the transmission of the virus (e.g. condoms, non-reusable syringes)	NHW	- DIST - Private Sector

	Activity	Primary Responsibility	Corollary Responsibility
II-7	Develop, implement, and evaluate pilot intervention programs targetted at injection drug users	NHW Provinces	- Municipalities - Community Groups
II-8	Develop and implement AIDS in the Work-place Information/Education Programs	Private Sector	- Provincial - Federal - Community groups
II-9	Enact liability legislation for breaches of confidentiality	Provinces	- Medical profession
II-10	Develop coordinated media approach	NHW	- Provinces - Private sector

5.0 THE BIO-MEDICAL CHALLENGE

Strategic Objective III:
Contribute to the Effort to Develop a Vaccine for HIV Infection and Therapies for AIDS-Related Diseases

RATIONALE

Canada must play a role in the effort to develop and assess a vaccine for HIV infection, and anti-viral and other agents and therapies to control and cure HIV infection/AIDS and its related diseases.

As noted in the Royal Society of Canada's report on AIDS (A Perspective for Canadians): "The development of vaccines, treatments and cures for HIV infection will depend very much on the willingness of society to give the necessary priority and support to its research scientists."

Much activity is already underway in this area, particularly by Health and Welfare Canada. These activities are noted in the following discussion and are considered to be part of the National Strategy.

5.1 Research and Support for National Reference Services

As indicated in 3.4, the nature of the virus requires the maintenance of a national reference service.

5.1.1 Laboratory Component of Clinical Trials

The anti-HIV agents (AZT and DDI) are inhibitory and do not appear capable of eliminating HIV from an infected person. The accurate

measurement of the efficacy of these drugs requires the coordination of a multidisciplinary approach. Not only must clinical end points be determined, but the correlation of specific laboratory markers with these clinical features must be developed. The National Health and Welfare Bureau of Laboratories and Research undertakes to coordinate these studies, ensuring that the effect of these agents on HIV and HIV-infected cells can be reliably measured. Methodologies will be developed and tested and, if found reliable, these technologies will be transferred to all appropriate testing centres across Canada.

The eligibility criteria for entrance into Clinical Trials often are predicated upon T4 cell numbers. Since the measurement of HIV's target cells is highly problematic and unstandardized, protocols relying upon T4 cell numbers to determine the effectiveness of potential drugs present considerable difficulty. The federal laboratories' representatives will work with centres undertaking Clinical Trials and National Health and Welfare will develop a consensus methodology for this procedure. Once a standardized protocol has been established and implemented, a quality assurance program will be undertaken by National Health and Welfare assuring Canada-wide applicability of results.

Partners with National Health and Welfare will include drug companies, Canada's Clinical Trial Network, provincial public health laboratories, university research scientists, and clinicians.

5.1.2 Animal Models

The effective and timely implementation of new antiviral agents and HIV vaccines will require the development of appropriate animal models. Novel research strategies and products must be assessed in appropriate animal models prior to the implementation of clinical trials in humans. When such strategies or products are developed by Canadian research scientists, or when Canada is asked to participate in such

trials on a multinational basis, National Health and Welfare will provide an appropriate testing centre for such agents. The Department maintains extensive primate facilities, and will make these available following appropriate review and consultation.

Since the assessment of anti-retroviral drugs is presently imperfect, it is necessary that appropriate animal models be utilized to study the efficacy of potential drugs. Several animal species have been successfully infected with HIV, but the deployment of facilities with sufficient biocontainment safeguards should be centralized due to the high hazards costs involved. If the proper animal models are utilized, the selection of drugs with potential for assessment in the clinical trials network could be facilitated.

5.1.3 New Procedures

Studies using technological advances claim to have identified a significant interval where individuals are infected but do not possess detectable antibodies to HIV. Since these findings have far-reaching implications for the Canadian Blood/Organ Donor Testing Program, public health programs, and Clinical Trials, properly designed "blinded" studies, must be implemented to test these claims. Multicentered evaluations will be coordinated by National Health and Welfare in order to assess the impact of these developments on Canada's health care system, including our supply of safe blood and blood products.

Partners with National Health and Welfare in such studies will include the Canadian Red Cross Society, the Provincial Public Health Laboratories, epidemiologists, and the investigators from the Clinical Trial Networks.

5.1.4 HIV-2

The laboratories of National Health and Welfare have identified five individuals infected with HIV-2 (as of October 1989), a virus distantly related to HIV-1 but which carries a disease indistinguishable from HIV-1. Since this virus cannot be reliably discerned by kits designed to detect HIV-1, the true prevalence of this agent is unknown.

National Health and Welfare will develop a strategy to assess the infiltration of HIV-2 into specific Canadian populations practicing high-risk behaviour. Since the commercial diagnostics for HIV-2 are not as reliable or available as those for HIV-1, National Health and Welfare will coordinate such studies and will continue to provide reference services for Canada. Such programs may well involve the cooperation of provincial public health laboratories, the Canadian Red Cross, the Bureau of Radiation and Medical Devices, and National Health and Welfare's Retrovirus and Immunology Laboratories.

5.1.5 Reference Services for Newborns

Several studies have now demonstrated that HIV-infection has spread into a small but significant number of pregnant Canadian women. Currently, the status of their children is unknown. Approximately 50% of children exposed to HIV will be infected and develop clinical signs. Studies designed to assess the impact of HIV upon newborns will involve clinicians, provincial public health authorities and National Health and Welfare laboratories. Evaluation of new technologies by National Health and Welfare and their implementation when appropriate, will eventually allow early intervention and treatment of children born of HIV-1 infected mothers.

5.1.6 Training

There already exists in Canada an effective laboratory network involving provincial public health laboratories, National Health and Welfare's Retrovirus and Immunology laboratories and other laboratory centres performing specialized functions. When new technologies are properly evaluated and standardized, they will be transferred to appropriate centres supported by training programs and national quality assurance programs administered by National Health and Welfare. In addition, consensus conferences targetted to methodological issues will be held to ensure that current technological information is available to all Canadian centres involved in clinical trials and HIV diagnosis.

5.2 Research Funding

The Royal Society of Canada has proposed a target of $35 million per annum for all research on HIV infection and AIDS. Recent Canadian assessments conclude that Canada's bio-medical funding vis-à-vis that in the United States appears to be considerably lacking.

Since success rates of individual projects are difficult to predict, funding levels should be assigned on a global basis and in the context of potential benefits. When a more reliable estimate of the HIV-infected population is developed in conjunction with more reliable costs of treatment, care and support, a more appropriate estimate of the bio-medical research effort can be calculated.

5.3 Scientific Resources

The number of research scientists in Canada working on HIV infection and AIDS-related work is small. Of these, many are also involved in clinical work and have other duties.

To encourage a larger pool of AIDS-specific research scientists, it is proposed that the National Fellowship Program be expanded. In addition, the concept of "centres of excellence" based in university, hospital and clinical facilities should be supported on a national and regional basis.

5.4 Coordination of Granting Programs

There are a range of potential granting programs for AIDS research. To improve effectiveness and efficiency, the National Strategy should encourage the principal granting programs - the National Health Research Development Program (NHRDP) and the Medical Research Council - to extend their collaboration and joint funding, and for other disciplinary granting agencies, such as the Social Science and Humanities Research Council, to participate in multi-disciplinary initiatives.

5.5 National Clearinghouse for Research

Because of the speed of development of HIV/AIDS research, a national clearinghouse should be established to track national and international research findings, research in progress, and calls for proposals.

This information should include traditional and non-traditional research and should be made available on an on-going basis to all organizations and individuals involved in AIDS prevention, treatment, care and support, as well as to AIDS researchers.

5.6 Joint Research Programs

To enlarge the pool of active research resources, and to promote new research initiatives in developing countries, the National Strategy should encourage Canada to initiate a Joint Research Program as part of the international effort to develop cures and therapies for HIV infection and AIDS-related diseases.

Strategic Plan/Objective III:
Bio-Medical Research

	Activity	Primary Responsibility	Corollary Responsibility
III-1	Develop a National AIDS Research Strategy (Biomedical)	NHW	- Provinces - Universities - Research Councils
III-2	Increase the annual amount of financial resources available for bio-medical research	NHW	- Selected provinces - Research Councils - Private Foundations - Pharm. Industry
III-3	Expand a National Fellowship Program for HIV/AIDS related research	NHW	- Universities - Research Councils - Provinces - Professional bodies
III-4	Initiate a study of the "Centre of Excellence" concept for scientific research and its extended applications	NHW	- Provinces - Universities
III-5	Develop a clearing-house for on-going national and international research findings and research in progress (Biomedical)	NHW Prof. Org.	- WHO/PAHO - Provinces - Universities
III-6	Develop a Joint Research Program to promote Canadian participation in international research projects	IDRC	- NHW - CIDA - External Affairs - WHO/PAHO - Research Councils

6.0 TREATMENT, CARE, AND SUPPORT SERVICES

Strategic Objective IV:
Ensure that Those Who are Infected and Their Supporters and Care-Givers have Access to Appropriate Treatment, Care and Support Services

RATIONALE

The organization and delivery of most treatment, care, and support services is a responsibility of provincial and territorial governments with the assistance of municipalities, non-governmental and community-based organizations and other partner agencies. Nevertheless there are aspects of HIV infection and AIDS and their consequent treatment, care, and support that require a national approach and federal involvement.

6.1 Drug Treatment and Clinical Trials

6.1.1 Access to New Treatments and Therapies

HIV infection is relatively new and complex and a national approach is required to ensure that state-of-the-art treatments, therapies and care are available to all Canadians. This requires that information on new findings and therapies be verified and distributed quickly and consistently to providers and patients.

6.1.2 Drug Regulation and Approvals

Governments in Canada do not direct or control the development of new drugs; drug development work is the responsibility of the pharmaceutical industry.

Strong liaison needs to be developed and maintained with the pharmaceutical industry to obtain early information concerning new therapies. This would enable the national regulatory system to anticipate and develop modalities for the earliest possible clinical research in Canada, providing a pre-eminent position for Canada for HIV/AIDS drug development work.

Early availability of HIV/AIDS drugs should continue to include the provision of "open arm" protocols for new drugs being assessed, or access via the Emergency Drug Release Program of National Health and Welfare when "open arm" trials are not available.

6.1.3 National Clinical Trials Network

A national clinical trials network for new drugs is being established to ensure that a "critical mass" of trial participants can be linked so that Canadians can participate in international clinical trials and have better access to experimental drugs. This network must be maintained and expanded as new drugs become available.

6.1.4 Costs of Drugs

Now that asymptomatic HIV-infected individuals can be aided by treatment with A.Z.T. and D.D.I., there is a particular need to ensure: i) all HIV seropositive individuals learn about their status and; ii) that treatment therapies are readily available to delay the progress of the infection and the development of opportunistic diseases.

One of the more difficult issues in the treatment area has been the costs of drug therapy. It is imperative that all HIV-infected persons have access to available drug therapies. The National Strategy should call for HIV and AIDS-related drug therapies to be made available free of charge, for the interim.

The cost of drugs during clinical trials are normally borne by the pharmaceutical industry. Reimbursement for drug costs occurs when the product has been sufficiently studied to permit the granting by National Health and Welfare of a "notice of compliance". This framework should be maintained for HIV/AIDS drugs.

By the provision of drugs, the effective overall costs of HIV infection/AIDS may be reduced and this aspect should be examined on an on-going basis by the Provincial and Federal Governments and should be considered in the economic analysis (Section 3.5).

The National Strategy should provide a clearing house function through which provincial governments and others can obtain information and can consult together on changing developments in this field. This function can be integrated with the other clearing house functions.

6.2 National Psycho/Social Research Networks

The research emphasis in Canada to date has largely focused on the bio-medical aspects of the disease. While this form of research is essential, further research that examines the social and psychological impacts of AIDS and HIV infection in various settings is necessary for developing effective counselling and treatment models, behavioural change approaches, and program planning and management at the community, regional and national levels. Special attention should be paid to the evaluation of current interventions.

A coordinated national approach to psycho-social research is required in order to more effectively use available research resources. This includes the development of appropriate research models, coordination and dissemination of research findings and support for participatory research studies at the local level.

6.3 Ensuring Access to Services

6.3.1 Inadequate Accessibility

Persons with HIV infection and AIDS often experience difficulties in obtaining health care and psycho-social services from doctors, dentists, hospitals and social services. These individuals also often experience difficulties in obtaining appropriate housing, financial and legal assistance, and other services necessary for day-to-day living.

Some of these inadequacies arise out of the scarcity of resources and funding, and inadequate coordination. Difficulties also arise out of discrimination. This discrimination is caused in part by the usual fear of infection, coupled with longstanding prejudice against the traditionally marginalized groups most affected by the infection. This reinforces the need for strengthened human rights legislation.

Service providers are also reluctant to enter the field because of the personal and financial costs involved. For example, doctors who treat HIV infected and PWA patients may lose some of their other patients. The doctors tend to spend much more time carrying out an insured activity with a PWA or HIV-infected person than they do with their other patients. The problem is compounded because doctors willing to treat HIV-infected and PWA patients tend to find that they get many more such patients. The complexity and rapidly changing nature of the disease and its treatments also demand more time from the physician to keep abreast of new developments.

Quebec, as an example, has moved to address this issue with respect to geriatric patients by providing for a differential remuneration to physicians. The National Strategy needs to address this issue with respect to HIV-infected and PWA patients.

6.3.2 Continuum of Care

The HIV epidemic highlights the need to reinforce and hasten the existing trend in the health and social services fields generally towards establishing continua of integrated services. Like many other life-threatening diseases, HIV infection requires an integrated multidisciplinary approach to treatment, care and support, including medical, nursing, psychological and counselling, social, housing, home and ambulatory care, financial and legal services.

Through case management and similar services, appropriate levels of treatment, care and support can be provided commensurate with the patient's changing condition. Medical and personal emergencies, and their attendant costs, can be alleviated using these types of services.

The National Strategy needs to address this issue which lies primarily within the jurisdiction of the provinces. The federal government also has a role, for example in assisting with the design and development of demonstration projects and of their evaluation.

6.4 Increasing Treatment, Care and Support

Those providing medical treatment, care and support services to PWAs and HIV-infected are already suffering from overwork and burnout. They report exceptional difficulty in recruiting other providers to assist them. But, the caseload is still small compared to the likely demand for services over the next five to ten years.

More resources will be needed to: (1) support those service providers who are overworked; (2) meet the increased demand as a result of greater numbers of PWA's and of those who are HIV antibody positive who remain in the chronic rather than acute and terminal phases of this

syndrome; and (3) provide home care, palliative and hospice care and related services for those who can live outside an institutional setting.

6.4.1 Human Resources

Additional human resources can be obtained in several ways. One way is to increase the numbers of providers from among those general practitioners, specialists, dentists, hospital staff, social service workers and others reluctant or refusing to provide services to those who are HIV positive. This may require addressing the issue of financial compensation referred to earlier (Sec. 6.3.1). To assist with problems of time management, a means of providing a "hotline" service on the status of therapies and treatments may be required. In addition, programs will be needed to create attitudinal changes amongst certain service providers.

The National Strategy will also have to address this supply question with professional health and social service schools and associations to incorporate the disease and its manifestations into their training, professional development and ethics programs.

6.4.2 Physical Resources

The delivery of health care services for HIV-infected persons and PWA's relies heavily on acute care hospital resources, often resulting in the inappropriate utilization of acute care beds already under severe pressure.

In the next few years, there will be a significant increase in the demand for curative, palliative and home care services, from a clientele which traditionally rarely used these services. The number of persons with HIV infection and AIDS will increase and their life expectancy will increase. But, a growing number of PWA's will likely become indigent

because of their deteriorating health and neurological condition. The demand will be aggravated by the increasing numbers of IV drug users who, typically, have fewer resources upon which to draw.

The National Strategy will need to address ambulatory and home care services for PWAs in order to improve the quality of their life and as a means of reducing the costs of the epidemic.

6.5 Community-Based and PWA Organizations

The AIDS and PWA committees in each province have done outstanding work to meet the needs of those who are infected. Within only a few years these organizations have grown to the point where they are an essential link in the continuum of treatment, care and support services. The services they provide - such as peer support, counselling, education, home care, case coordination, support to providers - are essential to persons who are infected, their families, loved ones and care-givers.

If these organizations are to continue with their responsibilities in assisting increasing numbers of persons with HIV infection and AIDS, they need sustaining funding, and assistance in improving their skills in organizational planning, volunteer recruitment and training, management, education programming and fund raising.

To date, community organizations have been assisted in the main by short-term federal funding, supplemented in some cases by funds from provinces, municipalities and the private sector. The National Strategy should call for provincial governments to accept a greater share of the responsibility for funding AIDS and PWA organizations within their jurisdictions, and for other areas, such as the private sector, to increase their funding support to these organizations.

Strategic Plan/Objective IV:
Treatment, Care and Support Services

	Activity	Primary Responsibility	Corollary Responsibility
IV-1	Establish and maintain a National HIV Clinical Drug Trials Network	NHW	- Provinces - Community groups - Universities - Pharm. Industry - Medical Profession
IV-2	Establish an "information hot line" service for physicians on the status of new HIV drugs/therapies	NHW	- Pharm. Industry - Physicians
IV-3	Publish a monthly newsletter on HIV Drugs/therapies	NHW	- Pharm. Industry - Physicians - Community groups - PWA's
IV-4	Facilitate the judicious, speedy release of new HIV Drugs	NHW	- Pharm. Industry
IV-5	Provide for access to new Drugs by PWA's, regardless of their ability to pay	Provinces	- Medical Profession - Pharmaceutical - NHW
IV-6	Provide a clearing house function for provincial collaboration on drug accessibility		
IV-7	Improve HIV/AIDS Education/Training in medical schools/schools of Social Work/Dentistry/Nursing	Professional Bodies (C.M.A., C.D.A., C.N.A., C.S.S.W.)	- Prov. Licensing Authorities - Provinces - Universities
IV-8	Develop a National (psycho-social) Research Strategy for HIV/AIDS	NHW	- Provinces - Universities - Research Councils
IV-9	Develop a clearing house for on-going National and International Research Findings and Research in progress (psycho-social)	Professional Bodies	- Provinces - Universities - Research Councils - NHW

	Activity	Primary Responsibility	Corollary Responsibility
IV-10	Expand the capability to provide palliative, hospice, home care and counselling services	Provinces	- Federal - Community groups
IV-11	Address discriminatory issues that affect access to health and social services and employment	- C.H.R.C. - Prov. Human Rights Bodies	- Prov. Licensing Authorities - Organized Labour - Business
IV-12	Provide support for national organizations primarily concerned with HIV/AIDS issues of national concern (e.g. Canadian AIDS Society, Canadian Hemophiliac Society, National PWA Coalition, etc.)	NHW	- Corporate/Voluntary Sector
IV-13	Provide sustaining funding for community-based AIDS organizations and P.W.A. Associations	- Provinces - Federal	- Private
IV-14	Increase alternate funding sources for community-based services	Private Sector	- Community groups - Voluntary Association
IV-15	Investigate with Canadian Medical, Canadian Dental, Canadian Hospital and other associations ways to improve services to HIV-infected and PWAs	Provinces NHW	- National Associations - Community group - PWA groups
IV-16	Establish a collaborative effort to reduce drug costs	Consumer and Corporate Affairs Drug Prices Review Board	- NHW - Provinces - Drug Companies

7.0 LEADERSHIP, PARTNERSHIP AND COMMITMENT

Strategic Objective V:
Strengthen National Mechanisms and Partnerships to Facilitate National Collaboration and Cooperation and to Maximize the Use of Available Resources and the Benefits of Collaboration and Cooperation

RATIONALE

This objective defines the commitment to the National AIDS Strategy. This commitment is to be demonstrated by the establishment of a national mechanism to provide direction and advice to the partners in the Strategy.

The operative principles in the management of the strategy should be that the various levels of government each do what they do best within their jurisdiction, supported by appropriate national, regional and local organizations, so as to avoid duplication and overlapping, maximize coordination, cooperation and collaboration and to optimize the effectiveness of available resources.

7.1 The Context

Federal Leadership

There is strong support at all levels for a coordinated National Strategy with Federal leadership.

Building on Existing Mechanisms

A great deal of work related to AIDS is being carried out across the country by the Federal, provincial and territorial governments, by some municipalities, by community and AIDS organizations, by organizations of Persons with AIDS, institutions, employers and others. The National Strategy should acknowledge and build upon these efforts.

Provincial Jurisdiction

Provinces fund and have jurisdiction over most of the services in the key areas of health, social services and education. As well, they have jurisdiction, in whole or part, over other key areas such as housing and human rights.

The management of the National Strategy should acknowledge and respect the autonomy and responsibilities of the provincial governments.

Partnership

The current structure for the funding of treatment, support and care represents a partnership among the parties: the federal, provincial and territorial governments, the national and community organizations and the care givers. The partnership must be sustained and nourished if the demands of the National AIDS Strategy are to be met.

7.2 Canadian Council on AIDS

In order to provide for the ongoing management of the National AIDS Strategy, the Working Document calls for the formation of a Canadian Council on AIDS.

7.2.1 Responsibilities

The responsibilities of the Council might include such activities as the following: to initiate, coordinate and evaluate policies and programs on a national basis; to assist in inter-regional activities; and to facilitate the efficient and effective use of financial and human resources in the implementation of the National Strategy.

The roles of Members of the Board of Directors would be:

1. To represent the perspectives of their jurisdictions on the Board;
2. To work with Board members to develop, implement and review the National Strategy;
3. To facilitate the implementation of the appropriate components of the National Strategy within their own jurisdictions.

7.2.2 Membership

The principle proposed for the composition of the Board of Directors is that it consists of representatives of governments and organizations which are accountable and which have established major responsibilities in the health, social services and education fields generally and with respect to AIDS particularly.

The Board of Directors would consist of:

* Federal/Provincial/Territorial Deputy Ministers of Health.
* A representative(s) of:
  - the Canadian AIDS Society
  - the P.W.A.s
  - the Canadian Hemophilia Society
  - Professional Associations (e.g. C.M.A., C.H.A., Dentists, Nurses, Social Workers, etc.).

- the Canadian Public Health Association.
- the Canadian Council on Social Development.
- Native Organizations
- Organized Labour
- Women's groups
- Business and employers
- Pharmaceutical Industry
- Life and Health Insurance Industry

7.2.3 Organization

The Council would consist of a Board of Directors, five sub-committees and an executive secretariat. The sub-committees would include: Bio-Medical; Surveillance and Epidemiology; Education and Prevention; Treatment, Care and Social Services; and Legal and Human Rights (see Annex A). The responsibilities of each sub-committee would be set out in the appropriate sections of the National Strategy.

It may be more appropriate for some of the organizations referred to in 7.2.2 to be represented on the Council through membership on one or more of the sub-committees rather than through membership on the Board of Directors itself. The sub-committees would also provide a place to incorporate experts and other key individuals into the consultation processes of the National Strategy.

The Board of Directors should consider establishing an Executive Committee of its key members to facilitate operational effectiveness.

7.2.4 Budget, Funding and Administration

The Council would be an independent entity. The suggested funding allocation is:

Federal Government	40%
Provincial Governments	40%
Non-Government	20%

The Council would be supported by an Executive Secretariat (10-12 persons), with a projected annual budget in the $2.5 to $3.0 million range.

The proposed initial time frame for the Council would be five years, with a formal review to be conducted at the end of the third year of operations.

Strategic Plan/Objective V:
Leadership, Partnership and Commitment

	Activity	Primary Responsibility	Corollary Responsibility
V-1	Establish a Canadian Council on AIDS (C.C.A.)	Minister of National Health and Welfare	- Provinces - Community groups/ PWA groups - Non-Government Voluntary Sector - Organized Labour - Business - Prof. Organizations
	Staff Executive Secretariat	Board of Directors of C.C.A.	
	Create five Standing Sub-Committees (Bio-Medical; Education/Prevention; Psycho-Social; Surveillance, and Epidemiology; Legal and Human Rights)	Board of Directors of C.C.A.	

ANNEX A

CANADIAN COUNCIL ON AIDS (PROPOSED)